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Mental health, hopelessness and quality of life in patients with retinitis pigmentosa

Vision-related mood and emotional health in retinitis pigmentosa

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Abstract
Aim: The aim of the study is to compare socio-demographic and clinical data, quality of life, psychiatric symptoms and hopelessness in patients with retinitis pigmentosa with healthy controls and to reveal factors associated with the quality of life and psychiatric symptoms in patients with retinitis pigmentosa.
Material and Methods: Seventy patients with retinitis pigmentosa and 70 age- and sex-matched healthy controls were admitted to this study. The Sociodemographic and Clinical Data Form, Brief Symptom Inventory, Beck Hopelessness Scale and Short Form-36 Quality of Life Scale were administered to all participants.
Results: Patients with retinitis pigmentosa had significantly higher unemployment levels, suicidal thoughts, and lower income compared to healthy controls. According to the Short Form-36 Quality of Life Scale results, lower mean scores were observed in patients with retinitis pigmentosa compared to controls in almost all domains. However, in almost all domains in Brief Symptom Inventory, higher mean scores were observed in patients with retinitis pigmentosa than in controls. Younger age of retinitis pigmentosa diagnosis, lower income and female gender were associated with lower physical quality of life, and lower monthly income, vision loss without blindness and higher depression levels were associated with lower mental quality of life in logistic regression analysis. Female gender and higher hope subscales scores of Beck Hopelessness Scale were associated with severity of psychiatric symptoms.
Discussion: The awareness of the factors associated with quality of life and psychiatric symptoms in patients with retinitis pigmentosa will increase the effectiveness of treatment options.

Keywords
Retinitis Pigmentosa, Mental Health, Quality of Life, Depression

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Introduction

Retinitis pigmentosa (RP) is a group of inherited diseases characterized by progressive photoreceptor degeneration. RP is usually diagnosed in childhood or young adulthood and leads to progressive vision loss. RP is a leading cause of blindness in younger individuals, and most patients lose their sight by the age of 40 [1]. The prevalence of RP is approximately 1/4000 [2]. Males may be affected a little more than females because of the X-linked form of the RP [3].

Vision loss may be the one that causes the most serious social and psychological disabilities among all sensory losses [4]. The psychological impact of vision loss has been investigated in numerous previous studies on age-related macular degeneration, glaucoma, diabetes-related retinopathy and other age-related eye diseases, which are associated with poor quality of life, anxiety, depression, and suicide [5, 6]. However, relatively few studies have investigated the effects of early-onset progressive vision loss on mental health, whose sample is predominantly young adults. Most of the small number of studies addressing mental health in younger visually impaired patients were conducted as qualitative studies with limited sample sizes without controls. When we compare RP with other ocular pathologies, the importance of defining the relationship between RP and mental health becomes clearer. For instance, in a study comparing glaucoma and RP, patients with RP were found to have a higher prevalence of depression [7]. In this context, it is crucial to diagnose and treat psychiatric disorders so that they can maintain adequate follow-up and treatment for RP and adjust to rehabilitation processes. There have been very few studies evaluating RP cases from a psychiatric perspective in the literature. The aim of the study is to compare socio-demographic and clinical data, quality of life (QoL), psychiatric symptoms and hopelessness in patients with RP with healthy controls and to reveal factors associated with the QoL and psychiatric symptoms in patients with RP.

Material and Methods

Participants and study design

Data were collected between 17 August 2016 and 30 September 2016 from 70 patients diagnosed with RP, who were followed up in outpatient clinics of Şişli Hamidiye Etfal Training and Research Hospital Ophthalmology Retinitis Pigmentosa. The diagnosis of RP was based on family history, fundus examination, genetic testing, and electroretinogram recording procedure prepared by the International Society for Clinical Electrophysiology of Vision. The control group consisted of seventy age- and sex-matched controls without any ocular or systemic diseases. The inclusion criteria were as follows: age over 18 years, diagnosis of retinitis pigmentosa, minimum primary education, and voluntary participation in the study. Participants were checked for the following exclusion criteria: Current major psychiatric disorders and patients with systemic and ocular diseases that could cause irreversible visual impairment. The purpose of the study was explained to the participants and informed consent forms were obtained for all participants before participating in the study. All participants completed sociodemographic and disease-specific questionnaires, Brief Symptom Inventory (BSI), Beck Hopelessness Scale (BHS), and Short-Form 36 Quality of Life Questionnaire (SF-36). Since there were visually impaired individuals in our study, these scales were read by a psychiatrist. This study was approved by the Ethics Committee of Health Sciences University Şişli Hamidiye Etfal Training and Research Hospital (16.08.2016/701) and conducted in accordance with the Declaration of Helsinki Ethical Principles.

Measurements

Socio-demographic and Clinical Data Form was formed by the authors includes socio-demographic characteristics (age, gender, household members, marital status, employment status, educational status, monthly income, social support), suicidal thoughts and information about the disease (age of RP diagnosis, age of visual loss, visual impairment). According to International Council of Ophthalmology (ICO) standards, RP patients were divided into two groups as those with blindness and vision loss (limited visual impairment and low vision) [8].

Brief Symptom Inventory (BSI) [9] is a scale of 53 items selected from the Symptom Check List (SCL-90-R) in order to capture psychiatric problems in various medical conditions. Respondents indicate the degree to which they suffered from each symptom over the past week, with responses ranging from 0 (not at all) to 4 (extremely). Symptoms are divided into nine subscales representing the domains of psychopathology: Somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, anger–hostility, phobic anxiety, paranoid ideation, and psychoticism. Four additional items do not factor into any of the dimensions but are included because they are clinically important such as questions about sleeping problems or guilt. The BSI profile produces three global indices of distress, including the Global Severity Index (GSI), Positive Symptoms Total Index and Positive Symptoms Distress Index. The GSI is the most sensitive indicator of a respondent's distress level, combining information about the number of symptoms and distress level. In this study, an average score for each scale was calculated. A higher score indicates more psychiatric symptoms. The Turkish version of BSI has good reliability and validity properties [10].

Short-Form 36 Quality of Life Questionnaire (SF-36) is a 36-item self-assessment scale that evaluates QoL based on eight health-related dimensions: physical functioning (PF), social functioning (SF), role physical (RP), role emotional (RE), mental health (MH), vitality (VT), bodily pain (BP), and general health (GH). The eight domains provide information on two main components: the Physical Component Summary (PCS; PF, BP, RP, and GH) and the Mental Component Summary (MCS; RE, SF, MH, and VT). Each subscale is scored between 0-100. Higher scores indicate higher levels of health and functionality. The reliability and validity of the Turkish translation have been established [11].

Beck Hopelessness Scale (BHS) [12] is a scale developed by Beck et al., which aims to measure the future expectations and pessimism level of individuals. It consists of 20 items related to emotions about the future, motivation loss, and hope. A total score is calculated by summing the pessimistic answers for each of the 20 items, with each optimistic response being scored as 0 and each pessimistic response as 1. High scores show that the hopelessness of the individual is high. The validity and reliability study of the scale for Turkey was performed [13].

Statistical Analysis

The collected data were analyzed using the Statistical Package for the Social Sciences version 20.0 (SPSS 20.0, Chicago, IL, USA). Descriptive statistics were presented as frequency, percentage, mean and standard deviation. The Chi-square test or Fisher Exact test were used to determine possible differences between groups in terms of categorical variables. The normality of distribution for continuous variables was tested with Kolmogorov–Smirnov test. Student's t-test was used for comparisons of variables when parametric assumptions were met. The Mann–Whitney U test was used to compare not normally distributed variables. Multiple logistic regression models were generated by gender, age, age of RP diagnosis, age of visual loss, visual impairment, monthly income, BSI-Depression and BHS-Hope for SF-36-PCS, SF-36-MCS and BSI-GSI. The significance level for logistic regression analysis was set at $p < .05$. The variables assessed were determined by clinical experience and a review of the literature as significant variables derived from our results.

Results

Seventy patients with RP and 70 controls were included in the analysis. Among the 70 patients with RP, 29 were women and the mean age was 44.4±13.4 years. Among the 70 healthy controls, 29 were women and the mean age was 44.4±13.3 years. Patients with RP and control subjects did not significantly differ in gender, age, educational status, marital status, or social support (p>0.05). Patients with RP had significantly higher unemployment (p=0.004) level, suicidal thoughts (p=0.012), and lower monthly income (p=0.046) compared to healthy controls. Among the 70 patients with RP, 43 were blind. The mean age of RP diagnosis was 22.7±15.8, and the mean age of vision loss was 35.8±14.0 years. The socio-demographic and clinic characteristics of the participants included in the study are summarized in Table 1.

When the BSI subscales of the patient and control groups were examined, obsessive-compulsive (p<0.001), interpersonal sensitivity (p<0.001), depression (p<0.001), anxiety (p<0.001), hostility (p=0.005), phobic anxiety (p<0.001), paranoid thoughts (p=0.006) and psychoticism (p=0.011) were found to be significantly higher in patients with RP than in the healthy controls. There was no difference in somatization and additional items (Table 2).

There was no statistically significant difference in hopelessness total score between the patients with RP and healthy controls. When the BHS subscales were compared, the hope subscale scores were significantly higher in the patients with RP than the healthy controls (p=0.044) (Table 2).

When the SF-36 subscales were compared between patients with RP and control groups, participants patients with RP reported lower mean scores on PF (p<0.001), RP (p<0.001), GH (p<0.001), VT (p<0.001), SF (p<0.001), RE (p=0.003) and MH (p<0.001) than those controls (Table 2).

Regression analysis was performed for SF-36-PCS (physical QoL), SF-36-MCS (mental QoL) and BSI-GSI (severity of psychiatric symptoms) in patients with RP. The results are summarized in Table 3. Younger age of RP diagnosis, lower monthly income and female gender were associated with poorer physical QoL (R2=0.313, F(7,62)=4.03, p<0.001), and lower monthly income, vision loss without blindness and higher depression levels were associated with worst mental QoL (R2=0.541, F(7,62)=10.44, p<0.001). Female gender and higher hope subscales scores of BHS were associated with severity of psychiatric symptoms (R2=0.359, F(7,62)=4.88, p<0.001).

Discussion

This study aims to determine the differences between the patients with RP and the healthy controls in terms of psychiatric symptoms, hopelessness and QoL, and to reveal socio-demographic, psychiatric symptoms and clinical characteristics associated with QoL. To our knowledge, this is the first study to compare the mental health, hopelessness, and QoL of patients with RP with healthy controls in Turkey. The main findings of the study were that patients with RP had significantly higher

Table 1. Comparison of sociodemographic and clinic data between patients with RP and controls

	Patients with RP n=70		Controls n=70		p
	n	%	n	%	
Gender					
Male	41	58.6	41	58.6	1.000
Female	29	41.4	29	41.4	
Marital Status					.
Married	47	67.1	49	70.0	0.785
Unmarried	23	32.9	21	30.0	
Household members					
Alone	3	4.3	8	11.4	0.343
Only the spouse	9	12.9	10	14.3	
Spouse and children	34	48.6	37	52.9	
Parents	14	20.0	8	11.4	
Other	10	14.3	7	10.0	
Education					
Primary school	33	47.1	35	50.0	0.993
High school	22	31.4	20	28.	
College or university	8	11.4	8	11.4	
Other	7	10.0	7	10.0	
Employment					
Yes	31	44.3	50	71.4	0.004*
No	39	55.7	20	28.6	
Social support					
Yes	43	61.4	39	55.7	0.493
No	27	38.6	31	44.3	
Income (monthly)					
Low	46	65.7	21	30.0	<0.001**
High	24	34.3	49	70.0	
Suicidal thoughts					
Yes	17	24.3	6	8.6	0.012*
No	53	75.7	64	91.4	
Visual impairment					
Blindness	43	61.4			
Vision lossa	27	38.6			
Age, Mean±SD, years	44.4±13.4		44.4±13.3		1.000
Age of RP Diagnosis Mean±SD, years	22.7±15.8				
Age of Vision Loss Mean±SD, years	35.8±14.0				

** p<0.001, * p<0.05. RP: Retinitis pigmentosa. a: Limited visual impairment and low vision

Table 2. Comparison of BSI, BHS and SF-36 Scale scores between patients with RP and controls

	Patients with RP n=70	Controls n=70	p
	Mean±SD	Mean±SD	
BSI			
Somatization	3.6±3.6	2.6±2.7	0.070
Obsessive compulsive disorder	5.8±3.5	3.5±2.8	<0.001**
Interpersonal sensitivity	4.5±2.8	2.6±2.2	<0.001**
Depression	5.9±4.1	2.7±2.9	<0.001**
Anxiety	4.4±3.3	2.0±1.9	<0.001**
Hostility	3.2±2.8	2.1±2.1	0.005*
Phobic anxiety	3.7±2.9	1.3±1.4	<0.001**
Paranoid thoughts	4.7±3.2	3.3±2.7	0.006*
Psychoticism	1.5±1.6	1.1±2.0	0.011*
Additional items	2.3±2.5	1.8±1.8	0.499
Global severity index	0.7±0.4	0.4±0.3	<0.001**
BHS			
Total	5.0±6.1	4.1±4.0	0.802
Feelings for future	1.0±1.7	1.0±1.5	0.295
Motivation Loss	1.7±2.6	1.3±1.7	0.933
Hope	1.9±1.6	1.3±1.1	0.044*
SF-36			
Physical Functioning (PF)	71.6±28.5	89.4±12.8	<0.001**
Role Physical (RP)	20.7±37.8	88.9±26.1	<0.001**
Bodily Pain (BP)	68.2±23.7	75.9±16.6	0.195
General health (GH)	52.7±23.0	76.4±18.9	<0.001**
Vitality (VT)	57.5±20.1	73.1±17.3	<0.001**
Social Functioning (SF)	73.4±21.7	86.6±15.2	<0.001**
Role Emotional (RE)	70.6±41.9	92.2±19.0	0.003*
Mental Health (MH)	65.5±18.7	77.7±16.7	<0.001**
Mental Component Summary (MCS)	66.7±20.9	82.4±13.3	<0.001**
Physical Component Summary (PCS)	53.3±18.2	82.6±14.5	<0.001**

BSI: Brief Symptom Inventory; BHS: Beck Hopelessness Scale; SF-36: Short Form-36 Quality of Life Scale. ** p<0.001, * p<0.05.

unemployment, suicidal thoughts, and lower monthly income than control subjects. Patients with RP had significantly PF, RP, GH, VT, SF, RE, and MH lower scores than healthy controls. Higher hope subscale scores of BHS and female gender were associated with severity of psychiatric symptoms.

The socioeconomic inequalities of patients with RP emphasize the importance of rehabilitation. However, there is limited knowledge about education, employment, and income of patients with RP. A few studies focusing on socio-economic characteristics in RP patients have indicated that patients have low education levels and income [14]. Similar to these results, in this study, lower monthly income and employment were found in patients with RP. The lower income in patients with RP may be a direct consequence of the lower level of employment. However, the fact that lower monthly income in patients with RP is associated with both physical and mental QoL highlights the importance of socio-economic parameters. Consistent with the literature, findings from this study indicate that patients with RP are in an underprivileged position in terms of some socio-economic parameters.

Studies on the relationship between vision loss and mental health have revealed that irreversible vision loss has permanent negative effects on mental health [15]. However, there have been limited studies in the literature examining mental health in patients with RP. In this study, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid thoughts and psychoticism scores were significantly higher in the patients with RP. These results corroborate the findings of a great deal of the previous studies in patients with vision loss in terms of mental health. In a study investigating psychiatric symptoms in 48 patients with inherited retinal diseases, increased phobic anxiety symptoms and paranoid thoughts were reported compared to healthy controls [16]. A study conducted with 417 RP patients revealed obsessive-compulsive disorder in 39.3%, hypochondriasis in 35.3%, depression in 31.2% of cases [17].

Visual impairment affects the daily life of patients, and it has been reported that the prevalence of depression is higher in visually impaired patients due to various reasons [18]. Depression in people with visual impairment often goes undetected and untreated. In these people, it is difficult to distinguish chronic depression from a normal part of the grieving process associated with vision loss. In the study by Papadopoulos et al. [18], 23.5% of participants with visual

Table 3. Factors associated with the quality of life and psychological symptoms in patients with RP

	SF-36-PCS			SF-36-MCS			BSI-GSI		
	B	SE b	β	b	SE b	β	b	SE b	β
Gender1	-10.353	4.801	-0.281*	0.485	4.488	0.011	0.358	0.096	0.444***
Age2	-0.057	0.302	-0.041	-0.173	0.282	-0.111	0.000	0.006	-0.006
Age of RP Diagnosis2	0.391	0.177	0.338*	0.286	0.166	0.216	-0.006	0.004	-0.210
Age of Visual Loss2	-0.468	0.305	-0.359	-0.151	0.285	-0.101	0.001	0.006	0.024
Visual impairment3	2.376	4.812	0.064	-15.959	4.499	-0.374**	-0.070	0.100	-0.086
Income4	10.050	4.440	0.263*	10.675	4.150	0.244*	-0.180	0.092	-0.215
BSI-Depression	-1.060	0.547	-0.238	-3.365	0.511	-0.659***	-	-	-
BHS-Hope	-	-	-	-	-	-	0.050	0.020	0.269*
R2	0.313			0.541			0.359		
F	4.03***			10.44***			4.88***		

PCS: Physical Component Summary; MCS: Mental Component Summary; GSI: Global Severity Index; BSI: Brief Symptom Inventory; BHS: Beck Hopelessness Scale; SF-36: Short Form-36 Quality of Life Scale. 1: (male=0, female=1); 2: (years); 3: (blindness=0, Vision loss (Limited visual impairment and low vision)=1); 4: (low=0, high=1) b, regression coefficient; SE b, standard error of the regression coefficient; β, standardised regression coefficient; R2=variance. *: P<0.05; **: P<0.01; ***: P<0.001.

impairment had mild depression and 6.5% had moderate or severe depression. Another study by Moschos et al. [19] found that 23.5% of patients with RP had mild depression, 26.5% had moderate depression and 26.5% had severe depression . To our knowledge, there is only one study focusing on suicidal thoughts in patients with RP. In that study [20], patients with RP reported higher levels of depression and suicidal thoughts than the general population, similar to our findings. Since there is indirect evidence that depression can be successfully treated and improved vision-related functions in patients with RP, it is very important to detect and treat depression in these patients. In studies investigating the association of retinitis pigmentosa and anxiety, the prevalence of anxiety was found 37% in patients with RP [21]. This study confirms that anxiety is more common in patients with RP.

Hopelessness is defined as the presence of negative beliefs about the future, pessimism and loss of expectations about the future [22]. In this study, there was no difference between the patients with RP and the control group in terms of hopelessness, but hope, one of the subscales of hopelessness, was higher in the patient group. In addition, hope subscales scores of BHS were associated with the severity of psychiatric symptoms. Although there was no attempt to examine hopelessness in RP patients, in a study conducted with university students with vision loss, 14.6% felt hopeless and there was no statistically significant difference compared to the healthy group [23]. As a result of clinical observations, a sense of hope plays an important role in protecting individuals' mental health. In this context, we suggest that the high hopelessness level in RP patients is associated with depression in this study. From this point of view, it can be said that depression and hopelessness in RP patients negatively affect the individual's self-confidence and adjustment in social life, thus making it difficult to make a plan for the future.

This study supports findings from previous studies, which have demonstrated patients with RP had lower levels QoL compared to healthy controls. It has been suggested that there is a significant negative correlation between the QoL score and the degree of visual field loss [24]. To date, too little attention has been paid to explore predictors of QoL in RP. In this study, younger age of RP diagnosis, lower monthly income and female gender were associated with lower physical QoL, and lower monthly income, vision loss without blindness and higher depression levels were associated with lower mental QoL in logistic regression analysis. There have been different results regarding visual function and QoL due to the use of various measures. For instance, the visual field and visual acuity of patients with RP correlated with the National Eye Institute Visual Function Questionnaire (NEI-VFQ). However, the same variables did not correlate with the World Health Organization Quality of Life Scale-Short Form (WHOQOL-BREF) in patients with mixed retinal dystrophy [25]. Surprisingly, loss of vision without blindness was found to be associated with mental quality of life in this study. This finding might be associated with a loss of confidence due to progressive loss of vision, which causes a lack of independence.

A number of limitations need to be noted regarding the present study. First, this study has several limitations regarding its cross-sectional type and lack of a longitudinal follow-up. Therefore, only a relationship can be implied in the study, not causality. Second, self-assessment scales were used in the study. Participants may often be biased when they report on their own experiences.

Conclusion

This study showed that patients with RP had socio-economic difficulties, lower quality of life, and higher psychiatric symptoms compared to healthy controls. Moreover, female patients with RP were at greater risk for poor mental QoL and severe psychiatric symptoms. The quicker and easier diagnosis of factors related to the quality of life and psychiatric symptom levels in patients with RP will increase the effectiveness of treatment options. In addition, this study revealed the importance of regular psychiatric examination in RP patients in order to improve the quality of life of individuals in the process of progressive vision loss and to enable them to better adjust to social life.

Scientific Responsibility Statement

The authors declare that they are responsible for the article's scientific content including study design, data collection, analysis and interpretation, writing, some of the main line, or all of the preparation and scientific review of the contents and approval of the final version of the article.

Animal and human rights statement

All procedures performed in this study were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. No animal or human studies were carried out by the authors for this article.

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Conflict of interest

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